



## TOOLBOX

# Sexual problems of disabled patients

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Many disabling conditions can produce sexual problems in men and women, including problems of desire, arousal, orgasm, or pain. Sexual difficulties may arise from direct trauma to the genital area (due to either accident or disease), damage to the nervous system (such as spinal cord injury), or as an indirect consequence of a disability. For example, cancer of any organ may not directly affect sexual abilities but can cause fatigue and reduce the desire or ability to engage in sexual activity. Similarly, psychological aspects of the disability, such as the dependence on others or one's own self-image, can profoundly disturb sexual arousal and function. The two main points for consideration are how disabling conditions affect sexual function and behavior and which sexual difficulties most commonly arise.

### Effects of disability on sexual function

Women who undergo radical mastectomy or a disfiguring trauma often report concerns about their femininity and self-image, such as feelings of lowered self-worth or the fear that men will find them less attractive. Similarly, after disfiguring surgery, traumatic accidents, or experiences with erectile dysfunction, men often avoid intimacy and the opportunity to meet potential partners because of embarrassment. "Sexuality" encompasses the entire view of how people express what is sexual, a combination of all the physical, emotional, intellectual, and social factors that have influenced their development. A person who has either lost a body part or is not able to use a part of his or her body may still have sexual feelings, may still desire sexual relationships, and may still seek sexual stimulation. Defining sexuality more broadly than just its physical function is particularly important for people with disabilities.

### Congenital disability

Congenital or birth impairments often affect all aspects of sexual development. Foremost is the lack of privacy and independence that accompanies both physical and cognitive dis-

abilities. This problem can be particularly severe for disabled adolescents, who often miss out on normal sexual experiences. Cognitively impaired patients often receive little attention to help them explore issues of their sexual health. The patient (or parents or caregivers if the patient is unable) needs to be educated about both normal sexual development (menses, erections, etc.) and alterations that might result from the disability. Issues of masturbation, unwanted pregnancy, and sexual abuse need to be discussed in an open and value-free environment.

In contrast, acquired disabilities may have different implications. Impairments early in life can make people less confident sexually and reduce their expectations for what is open to them sexually in their relationships. Patients who become disabled in adulthood are much more aware of what has been lost. While the degree of adjustment to congenital and acquired disabilities may not be different, the process of adjustment can vary greatly. For example, men with cardiac difficulties such as angina often present with sexual problems because they are worried about bringing on an attack if they attempt lovemaking. Similarly, women with joint difficulties (such as rheumatoid arthritis and osteoporosis) may find sexual positioning painful and so avoid activity. In both cases, the patient may be extremely hesitant to bring up a discussion of sexual function, and may suffer unnecessarily.

### Hidden impairment

Patients with an impairment that is hidden from others but which affects continence or sexual function often find the situation humiliating and avoid all social contact. For example, people with spina bifida and perineal paraplegia often walk without apparent difficulty, leading the public to be unaware of a disability. Despite their ability to be perceived as "normal," they experience problems with sexual functioning and with controlling their bladder and bowel. The unpredictability of control often

leads them to avoid social mixing, intimacy, and sexual interactions, all of which increases their isolation. It is not uncommon for people with even relatively minor disabilities to present with a low self-confidence and a poor body image. Clinicians should take care not to confuse the severity of a disability with the severity of its impact on the patient (see Table 1).

### Deteriorating conditions

In most cases of trauma, patients experience a loss that does not deteriorate, such as spinal cord injury or amputation. Some conditions, like multiple sclerosis, do deteriorate in either a stepwise or a gradual manner that requires mental adjustment to the initial diagnosis, and then constant reappraisal as the condition worsens. Sexual dysfunction may occur in multiple sclerosis initially as a direct result of demyelination of the nerve. It may also result through nonspecific indirect effects as the condition deteriorates or as a result of psychological effects stemming from poor self-image or from depression. There may be problems with other organ systems, as well



Patients with an impairment that is hidden from others but which affects continence or sexual function often find the situation unbearable.

Detail from *Boors carousing* by David Teniers the younger, 1664

### Causes of erectile dysfunction

- Psychological factors are among the most common factors for erectile dysfunction
- Lesions in the anterior temporal lobe (vascular, traumatic, etc.)
- Complete suprasacral spinal cord lesion, which permits only reflexogenic erection
- Incomplete suprasacral spinal cord lesion, which allows erection of either reflexogenic or psychogenic origin
- Complete infrasacral spinal cord lesion, which abolishes erection
- Autonomic neuropathy leads to impotence (such as in diabetes)
- Radial pelvic surgery can cause damage to the local nerve plexus (such as abdominoperineal resection of the rectum)
- Drugs that inhibit the action of acetylcholine
- Major vascular occlusion in the abdomen or pelvis, which impedes blood supply to penile tissue
- Fibrous plaques of Peyronie's disease and damage to the cavernosal tissue after prolonged priapism can be a major problem

as fatigue, anxiety, and altered desire in the patient's partner.

Healthcare providers caring for the disabled must address the sexual needs of the patients and their partners. The partner may not only have a reduced attraction to a disabled partner but also may have fears of hurting or otherwise making the partner uncomfortable. Issues of guilt, anxiety, and unfulfilled sexual desire may also be woven in with these concerns.

Ideally, conversations about sexual behaviors and feelings should take place with both the patient and the partner present, in order to clear up confusion and misunderstanding. The patient or the partner may prefer to discuss these issues in private, however, and it behooves the physician to open the door to such discussions.

### Mental impairment

Some conditions, such as Huntington's chorea and traumatic brain injury, may alter a patient's ability to think in a reasoned way, and these conditions can affect sexual behavior. Injury to the reticular activating system of the pons and mid-brain slows arousal, whereas injury to the frontal lobes may result in promiscuity because of reduced inhibition. Indirect effects of brain injury, such as alteration of endocrine function (for example, posttraumatic hypopituitarism), can also affect sexual drive and arousal.

People with learning difficulties often have problems developing an understanding of their

sexual identity. This may be a direct consequence of their learning impairment or a result of overprotection by their families. Parents and caregivers often feel uncomfortable with a child's developing sexual behavior, possibly because of fear of exploitation or because of their own lack of understanding or acceptance of the child's sexual needs. The patient's primary care physician is often the person to whom family members first mention their worries, or the physician may be the first person to raise the issue. Unfortunately, the concept of anticipatory guidance—providing education about expected developmental milestones and anticipated problems—so common in pediatrics is rarely considered by caregivers of the developmentally disabled. Primary care providers should be familiar with common concerns about sexuality experienced by both disabled persons and their parents. Topics such as masturbation, pregnancy prevention/family planning, and sexual abuse certainly deserve discussion at the appropriate time.

### Common sexual difficulties

Disabled persons may have never had a specific sexual experience (primary impairment) or may have become unable to continue with their sex life (secondary impairment). Primary functional impairments—such as a man's inability to get an erection or to ejaculate or a woman's pain, inability to allow penetration, or anorgasmia—are more common among patients with long-standing disabilities or those of early onset and are often hard to resolve. Men are more likely to present than women, possibly reflecting cultural perceptions of the importance of sexual performance and, now, the greater range of treatment options available (see Table 2).

Sexual function and arousal in men and women occur in response to reflexogenic genital stimulation or psychogenic desire in those with intact sexual drive mechanisms. Those with brain or spinal cord injury, or those whose injury or disease processes affect the spinal cord, experience partial or complete loss of sexual functions. They require comprehensive assessment of the level and degree of damage to the brain and nerve cord and the damage to upper and lower motor neurons (by testing the bulbocavernosus and anal wink reflexes). In neurological terms, male erection is similar to the female vasocongestive response and lubrication, while male ejac-

ulation is similar to female contraction of the pelvic floor, perineum, and anal sphincter.

### Erectile dysfunction

Loss of erectile function is the commonest sexual problem among disabled male patients. While the disabled may have a host of possible organic etiologies for erectile dysfunction, medication-related impairment is common and often easily corrected (see Figure 1). About 10% of commonly prescribed drugs produce erectile dysfunction.<sup>1</sup> These same drugs are used in disabled persons, and there is every reason to believe they have the same unintended side effects.

Even in cases of a clear physical cause, psychological factors are often also important. Physical loss of erection is most often treated by injection of drugs directly into the penis or, recently, with the oral drug sildenafil (viagra), which has been shown to enhance erectile ability in 70% to 90% of patients with spinal cord injuries, diabetes, and depression. Vacuum devices can be used by men who do not want to inject themselves, and there are topical preparations, but these are used less often because of their relative lack of success. Patients with erectile dysfunction of primarily psychological origin may benefit from a wide range of specialized psychological therapies, which usually include their partner.

### Orgasm in women

The concept of orgasm had originally been considered to involve a reflexive pathway. Further research in this area led to the identification of a sensitive area women feel through the anterior wall of the vagina (the "G-spot") which, when stimulated, produces a fluid chemically different from urine and which in turn leads to the phenomenon of female ejaculation. It has been

Table 1

### Key questions in cases of disability

#### Present condition

- Does the person have a congenital or acquired disability?
- Is the disability static or deteriorating?
- Is the disability observable by other people?

#### Effect of condition on sexuality

- Does the disability affect sexual function or sexuality?
- Does the disability impair cognitive or intellectual ability?
- Are there associated iatrogenic factors?
- Is fertility the principal concern?



Table 2 Assessing sexual problems in disabled patients

Mainly psychological cause of problem (Refer to psychosexual counseling)	Mainly organic cause of problem (Refer to suitable specialist)
Acute onset	Generally slower onset
Generally poor relationship with partner (refer for psychological counseling)	Good harmonious relationship with partner
Symptoms not consistent in all situations	Symptoms consistent in all situations and with all people
Major life events often present (births, deaths, potential or actual change in relationship, health, job)	Major life events rarely present
Coexisting problem with mental or physical health rarely common	Coexisting problem with mental or physical health present
Men with erectile dysfunction have nocturnal or early morning erections	No nocturnal or early morning erections in men with erectile dysfunction
Can respond to self-stimulation	No response to self-stimulation
Commonly aged $\leq 50$ years	Commonly aged $\geq 50$ years
Genitalia (including prostate) and secondary sexual characteristics seem normal	Genitalia and secondary sexual characteristics show abnormal structure or development
Normal results from investigations*	Abnormal results from investigations

\*Complete blood count; blood urea and nitrogen (BUN); urinalysis; liver function; and thyroxin, glucose, and sex hormone concentrations.

hypothesized that there are two different pathways involved in the sexual responses of women: clitoral stimulation provides arousal via the pudendal nerve and vaginal stimulation induces arousal via the hypogastric plexus and pelvic nerve.

Women with various complete neurological injuries to their spinal cords, however, often report the continuation of the experience of orgasm on vaginal stimulation. It has, therefore, been hypothesized that a third sensory pathway, the vagus nerve, which directly links the cervix to the brain and bypasses the spinal cord, enables orgasm in these women.

### Difficulties with ejaculation

Ejaculatory dysfunction among disabled people is most common in men with spinal cord injury, multiple sclerosis, spina bifida, and transverse myelitis. Ejaculation involves closure of the bladder neck (through sympathetic stimulation) and relaxation of the external sphincter.

Patients with spinal damage often experience retrograde ejaculation into the bladder because of sympathetic damage, and various procedures have been used to induce an ejaculate for patients who want to have children. In men with an upper motor neurone lesion but with an intact sacral cord, vibratory stimulation is often used.

After training, vibratory stimulation of the penis can be attempted at home. Once the frequency and amplitude of the vibration have been selected, the vibrator is applied to the penis to stimulate the pudendal nerve.

If this is unsuccessful, patients with lower motor neurone injuries can be helped by electroejaculation. This involves the insertion of a

stimulatory probe into the rectum to stimulate the midsacral roots directly, but it requires hospital attendance because of the complexity of the procedure and the potential side effects of pain and autonomic dysreflexia.

### Fertility problems

For men with neurological impairment, obtaining semen with a reasonable sperm count and motility is a problem. The same difficulty occurs with many other injuries and as a side effect of drugs used to treat various conditions.

Women with traumatic brain injury, epilepsy, multiple sclerosis, and diabetes retain an anatomically intact reproductive system, but the physiological effects of their condition may alter ovulation or hormone secretion. The lower pregnancy rates reported in disabled women are probably the result of avoiding conception because of concerns over their ability to raise a family. It is important to assure that when the disabled person is cognitively intact, decisions about family planning, reproductive health, contraception, sexual orientation, and sexuality are made by that person, with all the attention to confidentiality and informed consent that would be offered to other sexually active persons. Those with congenital disorders known to affect fertility and childbirth should be given the opportunity to discuss any anxieties with a genetic counselor.

### Assisted conception

Technology exists to obtain ejaculate from most men, but the problem of semen quality, particularly sperm motility, remains. The reason for this is unclear, although scrotal hyperthermia,

long-term use of certain drugs, prolonged sitting in a wheelchair, and repeated urinary tract infections have all been suggested.

At the simplest level, couples can be taught how to obtain semen with a vibrator at home and introduce it into the vagina with a standard syringe. If sperm motility is low ( $<35\%$ ), in vitro fertilization can be useful. The process is also helpful for some men with spinal cord injury.

The recently developed techniques of micro-assisted fertilization require only small numbers of motile sperm. Intracytoplasmic sperm injection, in which semen is inserted directly into the egg cytoplasm, is more suited for those with low sperm counts.

Research indicates fertilization rates as high as 70% and childbirth rates as high as those with in vitro fertilization. Studies are currently assessing the effectiveness of using a small specimen of semen taken directly from the epididymis for in vitro fertilization or intracytoplasmic sperm injection.

Even in conditions of severe disability, such as tetraplegia, close monitoring by a team of specialists, including the spinal injury team and urological and gynecological services, should ensure maximum likelihood of conception and pregnancy. Options exist for improving sexual function and fertility for those with a wide range of disabling conditions. Such people do not wish for preferential treatment, but they do deserve equal opportunity and access to a fulfilling sex life.

#### Reference

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